

Digital Narratives

*Creating Diabetes Awareness through Testimonials and Communities of Faith*

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By

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## **Abstract**

The purpose of this project is to create a DVD of testimonial accounts that provide insights into "Living with Diabetes." Using video testimonials (digital narratives) from members of peer groups and trusted sources, particularly individuals who belong to communities of faith in the Greater Columbus area, were recorded. Ten out of the 13 testimonials used an intergenerational approach in which a younger participant interviewed a grand-parent figure. This project was initiated because, historically, African Americans have developed distrust for the medical community, which has created a communication barrier. This barrier has prevented many African Americans from receiving vital information on healthy lifestyle maintenance. However, there is substantial involvement in communities of faith (i.e., churches) amongst members of the African American community. The concept of channeling health information through trusted sources gave way to the Digital Narratives project. Through the Digital Narratives project, two or more people who attend local churches were filmed while conversing about their personal experiences with or questions about diabetes. The videos were shown to an audience at a culminating event at a local church and at other events. Informal feedback to the video testimonials was positive. The study contributes to the literature by providing a unique approach for message design that might be of effective in African American communities of faith.

This is a creative project with the DVD as the final outcome. The document provides a rationale for the creative project, the process of creating the DVD, a brief overview of the contents of the DVD and some preliminary evaluation.

## **Introduction**

People of African decent are disproportionately affected by both Type I and Type 2 diabetes as, compared to members of other ethnic groups around the world. Though diabetes is heavily influenced by an individual's genetic makeup and can occur hereditarily (Type I), one's lifestyle is the next most important factor in the development of Type 2 diabetes, (often referred to as adult onset diabetes). An unfortunate reality remains that even though people of African decent are more likely to have diabetes than others, this particular population is also less likely to be aware of diabetes symptoms, have access to information about maintenance or prevention, or seek medical attention for diagnoses and treatment. One factor that contributes to this awareness disparity is the distrust among African Americans of the biological medical community. Because of the historical experiences that African Americans have encountered when seeking medical attention from those in the medical profession (i.e., the Tuskegee Syphilis Experiment), the distrust (and sometimes fear) of seeking medical attention has survived for generations (Freimuth, et.al., 2001). It is important that the health disparities are addressed so that specific populations are made aware of their health risks, and may choose to take action on their own behalf.

In addition, people within this population tend to rely more heavily on their faith in the power of God to heal them spiritually and physically. There is often little distinction between spiritual health and physical health, as both are considered co-dependent and both depend on a relationship with God. Communities of faith,

particularly those that subscribe to Christianity, often rely on personal testimonials to deliver messages and influence behavior evaluation and change. During many church services, notably in predominately African American congregations, attendees are encouraged (and often expected) to testify, or give an account of a situation that they have experienced, and explain how their faith and blessings have helped them endure, overcome, or enjoy their circumstances. The testimonial can serve as a message or lesson to others that may one day encounter or have already encountered a situation similar to that told by the person testifying. It can also provide comfort, relief and reassurance to the person who delivers the testimony. Testimonies are considered evidence of an individual experiencing a higher power (whom will be referred to as God throughout this paper) working through his/her life. The goal of testimonies is to influence or encourage the audience to evaluate their behavior based on an account of someone else's experience, to reassure them that it is possible to endure difficult circumstances, or remind them to appreciate the positive occurrences in their lives.

Since testimonials have proven to be an effective form of communication for awareness, behavior change and evaluation, a variety of situations within trusted environments, it is plausible to consider that delivering diabetes information through testimonials from recognizable members of the community will prove effective in reaching this population. This approach assumes that, given the historical distrust of the medial community (through which most current diabetes information is delivered), African Americans will be more likely to trust information delivered by someone with whom they have interacted or can identify, or feel as though they can trust.

## **Literature Review**

A number of studies have examined the relationship between African American church members' beliefs and their perceptions of health. One such qualitative study conducted by Cheryl Holt and Stephanie McClure (2006) explores the relationship of religiosity/spirituality and health amongst African Americans, and how this relationship might influence the integration of church-based health interventions for African Americans in communities of faith. The study found that the majority of the population believes that mental health affects physical health, the church can be regarded as a family unit, the physical body is a temple of God, illness can serve as a message from God, an individual's personal (health) situation may reflect their lifestyle, religion can bring inner peace, difficult situations can be surrendered to God, spiritual health affects physical health, faith gives hope, and that there is a connection between mind, body and spirit (Holt and McClure, 2006).

Another qualitative study in 2006 by Rebecca L. Polzer explores how African Americans with type 2 diabetes view the spiritual role of health care providers and the effects of that role on self-management.

## **African Americans and Diabetes**

According to the CDC (Center for Disease Control, 2005), Type 2 diabetes is one of the leading causes for mortality and morbidity. The American Diabetes Association (2005) also points out that African Americans, American Indians, and Hispanic/Latino

Americans are at a higher risk of developing type 2 diabetes, and that, though unusual, it is being diagnosed more frequently among children within those categories (American Diabetes Association, 2005).

### **Church as a Social Change Agent**

In the 1998 article entitled *Church Culture as a Strategy of Action in the Black Community*, Mary Pattillo-McCoy points to the “Black church” as a source of familiarity, and an essential and ever-present aspect of Black culture. She mentions that it “provides a cultural blueprint for civic life in the neighborhood.” Individuals who are involved with or have established a connection with a community of faith (church), often look to others within those communities for social support and guidance (Pattillo-McCoy, 1998). The church has maintained itself as a necessity for sustenance of many members of the African American population. The Christian church particularly, has provided refuge for Africans displaced in America, and the tradition of joining the church has survived through generations. It is common for many African Americans to have a deep-seated trust and respect for the people and messages delivered within their churches. Thus, it can be inferred that communities of faith, such as the Christian church can have significant influences on the beliefs and behaviors of church members and affiliates.

### **General Diabetes Information**

Type 2 diabetes has been referred to as “non insulin-dependent diabetes mellitus

(NIDDM)" or adult-onset diabetes. It is responsible for 90% to 95% of all diagnosed cases of diabetes, and is a condition in which the body's cells do not process insulin properly. Type 2 diabetes is generally associated with older age, obesity, sedentary lifestyle (which leads to obesity), family history or diabetes (American Diabetes Association, 2005).

Type 1, also known as juvenile or insulin dependent diabetes is also more prevalent among people of African decent. Of those who identify themselves as non-Hispanic blacks, 3.2 million, or 13.3% of all aged 20 years or older, have diabetes, and Non-Hispanic blacks are almost twice as likely to have diabetes than non-Hispanic whites.

### **Summary Rationale for the Project**

Given the prevalence of diabetes amongst people of African decent, and the health disparities that exist due to communication barriers between that community and the medical community, and gaps in knowledge, it is important to implement new ways of conveying important healthcare information to the people within this population. Testimonials resonate with the church culture and can be effective in conveying messages to African Americans, particularly those who frequent church services or belong to communities of faith. Further, to address the problem of juvenile diabetes, the testimonial accounts were framed as inter-generational dialogues.

## **Process**

This project is comprised of two phases. Phase one included the creation of testimonials and the DVDs using a community-based approach. In the second phase, the DVD was presented to various audiences and informal feedback and evaluation was sought. Each phase relied heavily on active participation and ideas from members of the people within predominately African American communities of faith, in the Greater Columbus, Ohio area.

### **Phase One**

The creative component involved filming dialogues with African Americans who attend local churches, and who identify themselves as members of a community of faith (denominations not specified). Though we did not require that participants specify their denomination or expressly identify the community of faith to which they belong, all participants described themselves as followers of God and/or Christians. Most of the individuals who participated in the dialogues come from low-income neighborhoods in Columbus, OH. In cooperation with an umbrella organization for a network of local churches and the Ohio Commission on Minority Health, we recruited 24 individuals to participate in the dialogues. Each pair generally consisted of one older individual and one younger individual, with the exception of two pairs (one husband and wife, and two teenage girls), and two group conversations (three teenagers and one senior). The dialogue between the individuals was intended to create an atmosphere that encouraged questions and answers (i.e., the younger person asks the older person



questions, or the individual who had experienced diabetes would answer questions from the one who had not experienced diabetes). Nine of the thirteen dialogues filmed, took place at Columbus Public Health, and all participants volunteered their participation.

Before filming, we requested that everyone speak genuinely and extemporaneously about their personal experiences with diabetes. Some of the participants have been diagnosed with diabetes and spoke about the physical, emotional, and spiritual experiences they have had since their diagnoses. Others recounted the effect diabetes has had on their loved ones, and possibility of developing the disease themselves.

### **Institutional Review Board Approval**

Before evaluating the effectiveness of the videos, it was necessary to secure approval from the Institutional Review Board. The pre-, post- and video evaluations were submitted to the IRB for review prior to dissemination to participants. This step had to be completed in order to protect the participants from any undue harm during the research process, as well as increase credibility for the project.

Those who participated in the testimonial filming signed video release forms indicating their (or their parents') willingness to appear on film as part of this project.

### **Video Editing**

Editing the videos was one of the most challenging tasks in completing the DVD. Each dialogue (with the exception of four) featured a different pair or group of people

discussing their experiences with diabetes. To avoid redundancy, I omitted many portions of the videos where people mentioned similar issues. I paid close attention to the accuracy of the information each person delivered in their testimonial, omitted incorrect information, and made sure that the most compelling and relevant information was included in the final product. I emphasized key questions and statements by adding subtitles that coincided with the remarks. The addition of instrumental music was intended to create a subtle, calming ambience without overpowering the speakers' voices. Some of the participants were able to provide photos of themselves or the loved ones of whom they spoke. These photos enhanced the video presentation by allowing the viewer to visually connect with the situations mentioned during the testimonials.

The finished DVD includes 13 testimonial accounts of people in the Greater Columbus community who have experienced or have inquiries about diabetes. Each testimonial is based on the unique experiences of the people featured on the DVD. As the debilitating effects of diabetes arose during conversation, some of the people evoked a great deal of emotion while discussing the ways in which diabetes has negatively affected the health of their loved ones. Others mention their successes in managing the disease, and offer encouraging sentiments to those who may eventually experience diabetes. Diabetes prevention is mentioned often, and participants suggest a number of ways to decrease the chances of developing type 2 diabetes.

## **Phase Two**

One of the participating churches invited church and community members to an open community event on an evening in April. During this event, information from the medical community was disseminated to attendees, and medical and public health representatives presented information about diabetes management and prevention. To evaluate the level of awareness and effectiveness of the videos, we created a pre-questionnaire, post-questionnaire, and video evaluation. After each video, we asked participants to provide their opinions on the effectiveness of the video dialogue.

On two separate occasions, additional participants were asked to evaluate the effectiveness of the testimonial approach by completing qualitative questionnaires. A total of 68 respondents (males and females between the ages of 18 and 66 and over) viewed the testimonial videos, as well as a clip of endocrinologist, Dr. Kwame Osei, speaking about the prevalence of diabetes amongst people of African decent, diabetes symptoms, and ways to prevent and manage diabetes. Over three-fourths of this audience indicated that the videos were relevant to their personal situations, and they appreciate hearing about diabetes via the testimonial method.

## **Relevance**

An average of 65% of all participants agreed or strongly agreed that they could relate to the experience of people in the videos (testimonial and non-testimonial). The majority shared physical traits and a common faith as well. These factors are important in addressing the relevance of the videos to the target population.

## **Personal Impact of Videos**

Only those who viewed the testimonials were asked to evaluate each video they saw. Nearly 90% of viewers agreed or strongly agreed that both testimonials moved them, and about 89% agreed or strongly agreed that the testimonials were interesting. Similarly, about 89% agreed or strongly agreed that African Americans can identify with the dialogue in the videos. However, only 70% of viewers agreed or strongly agreed that the testimonials presented useful diabetes information. One viewer commented, "The stories were heartfelt, but neither of them said much about the actual disease... only what happened because of it."

## **Discussion**

Fortunately, the results of this study indicate that this segment of the African American population is likely to benefit from receiving diabetes information via digital narratives. While the results of this study conclude that the testimonial-based approach used to deliver diabetes information to African American communities of faith, in the Greater Columbus area is effective, additional work is required to determine other ways of increasing the effectiveness of the testimonials. Many challenges arose while soliciting responses from community members of different socioeconomic statuses, educational backgrounds, and literacy levels. Additional methods may include filming and showing monologues by a larger variety of people with type 1 or type 2 diabetes,

or monologues by people whose lifestyles demonstrate behavior that helps prevent the onset of type 2 diabetes.

Ideally, this study can be improved under conditions with fewer time constraints. While most of the emphasis was placed on creating a product to distribute to the community, in future studies, more attention should be paid to analyzing the effectiveness of the product (testimonials) on the target population, over a longer period of time. The immediate responses on the questionnaires do not necessarily reflect the population's intent to adopt or maintain healthy lifestyle behaviors, and is thus not an adequate predictor of the true effectiveness of the testimonial approach. Further suggestions include following up with those who participated in filming the videos, and with those who have viewed them, to determine whether the testimonial approach has influenced their lifestyles, if they have retained information from the videos, or if they have taken steps to seek more information about diabetes prevention and/or management. Though steps have been taken to decrease the health information disparity that exists within the African American community, statistics prove that the issue of diabetes amongst people of African decent still exists, and the problem must continue to be addressed through innovative methods of communication.

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